Caregiver Guide

Tips for Caregivers of People with Alzheimer's Disease

...from the National Institute on Aging

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Tips for Caregivers

Caring for a person with Alzheimer's disease (AD) at home is a difficult task and can become overwhelming at times. Each day brings new challenges as the caregiver copes with changing levels of ability and new patterns of behavior. Research has shown that caregivers themselves often are at increased risk for depression and illness, especially if they do not receive adequate support from family, friends, and the community.

One of the biggest struggles caregivers face is dealing with the difficult behaviors of the person they are caring for. Dressing, bathing, eating—basic activities of daily living—often become difficult to manage for both the person with AD and the caregiver. Having a plan for getting through the day can help caregivers cope. Many caregivers have found it helpful to use strategies for dealing with difficult behaviors and stressful situations. Following are some suggestions to consider when faced with difficult aspects of caring for a person with AD.

Dealing with the Diagnosis

Finding out that a loved one has Alzheimer's disease can be stressful, frightening, and overwhelming. As you begin to take stock of the situation, here are some tips that may help:

- Ask the doctor any questions you have about AD. Find out what treatments might work best to alleviate symptoms or address behavior problems.

- Contact organizations such as the Alzheimer's Association and the Alzheimer's Disease Education and Referral (ADEAR) Center for more information about the disease, treatment options, and caregiving resources. Some community groups may offer classes to teach caregiving, problem-solving, and management skills.
- Find a support group where you can share your feelings and concerns. Members of support groups often have helpful ideas or know of useful resources based on their own experiences. Online support groups make it possible for caregivers to receive support without having to leave home.
- Study your day to see if you can develop a routine that makes things go more smoothly. If there are times of day when the person with AD is less confused or more cooperative, plan your routine to make the most of those moments. Keep in mind that the way the person functions may change from day to day, so try to be flexible and adapt your routine as needed.
- Consider using adult day care or respite services to ease the day-to-day demands of caregiving. These services allow you to have a break while knowing that the person with AD is being well cared for.
- Begin to plan for the future. This may include getting financial and legal documents in order, investigating long-term care options, and determining what services are covered by health insurance and Medicare.

Communication

Trying to communicate with a person who has AD can be a challenge. Both understanding and being understood may be difficult.

- Choose simple words and short sentences and use a gentle, calm tone of voice.
- Avoid talking to the person with AD like a baby or talking about the person as if he or she weren't there.
- Minimize distractions and noise—such as the television or radio—to help the person focus on what you are saying.
- Call the person by name, making sure you have his or her attention before speaking.
- Allow enough time for a response. Be careful not to interrupt.
- If the person with AD is struggling to find a word or communicate a thought, gently try to provide the word he or she is looking for.
- Try to frame questions and instructions in a positive way.

Bathing

While some people with AD don't mind bathing, for others it is a frightening, confusing experience. Advance planning can help make bath time better for both of you.

- Plan the bath or shower for the time of day when the person is most calm and agreeable. Be consistent. Try to develop a routine.
- Respect the fact that bathing is scary and uncomfortable for some people with AD. Be gentle and respectful. Be patient and calm.
- Tell the person what you are going to do, step by step, and allow him or her to do as much as possible.
- Prepare in advance. Make sure you have everything you need ready and in the bathroom before beginning. Draw the bath ahead of time.
- Be sensitive to the temperature. Warm up the room beforehand if necessary and keep extra towels and a robe nearby. Test the water temperature before beginning the bath or shower.
- Minimize safety risks by using a handheld showerhead, shower bench, grab bars, and nonskid bath mats. Never leave the person alone in the bath or shower.
- Try a sponge bath. Bathing may not be necessary every day. A sponge bath can be effective between showers or baths.

Dressing

For someone who has AD, getting dressed presents a series of challenges: choosing what to wear, getting some clothes off and other clothes on, and struggling with buttons and zippers. Minimizing the challenges may make a difference.

- Try to have the person get dressed at the same time each day so he or she will come to expect it as part of the daily routine.
- Encourage the person to dress himself or herself to whatever degree possible. Plan to allow extra time so there is no pressure or rush.
- Allow the person to choose from a limited selection of outfits. If he or she has a favorite outfit, consider buying several identical sets.
- Arrange the clothes in the order they are to be put on to help the person move through the process.
- Provide clear, step-by-step instructions if the person needs prompting.
- Choose clothing that is comfortable, easy to get on and off, and easy to care for. Elastic waists and Velcro enclosures minimize struggles with buttons and zippers.

Eating

Eating can be a challenge. Some people with AD want to eat all the time, while others have to be encouraged to maintain a good diet.

- Ensure a quiet, calm atmosphere for eating. Limiting noise and other distractions may help the person focus on the meal.
- Provide a limited number of choices of food and serve small portions. You may want to offer several small meals throughout the day in place of three larger ones.
- Use straws or cups with lids to make drinking easier.
- Substitute finger foods if the person struggles with utensils. Using a bowl instead of a plate also may help.
- Have healthy snacks on hand. To encourage eating, keep the snacks where they can be seen.
- Visit the dentist regularly to keep mouth and teeth healthy.

Activities

What to do all day? Finding activities that the person with AD can do and is interested in can be a challenge. Building on current skills generally works better than trying to teach something new.

- Don't expect too much. Simple activities often are best, especially when they use current abilities.
- Help the person get started on an activity. Break the activity down into small steps and praise the person for each step he or she completes.
- Watch for signs of agitation or frustration with an activity. Gently help or distract the person to something else.
- Incorporate activities the person seems to enjoy into your daily routine and try to do them at a similar time each day.
- Take advantage of adult day services, which provide various activities for the person with AD, as well as an opportunity for caregivers to gain temporary relief from tasks associated with caregiving. Transportation and meals often are provided.

Exercise

Incorporating exercise into the daily routine has benefits for both the person with AD and the caregiver. Not only can it improve health, but it also can provide a meaningful activity for both of you to share.

- Think about what kind of physical activities you both enjoy, perhaps walking, swimming, tennis, dancing, or gardening. Determine the time of day and place where this type of activity would work best.
- Be realistic in your expectations. Build slowly, perhaps just starting with a short walk around the yard, for example, before progressing to a walk around the block.
- Be aware of any discomfort or signs of overexertion. Talk to the person's doctor if this happens.
- Allow as much independence as possible, even if it means a less-than-perfect garden or a scoreless tennis match.
- See what kinds of exercise programs are available in your area. Senior centers may have group programs for people who enjoy exercising with others. Local malls often have walking clubs and provide a place to exercise when the weather is bad.
- Encourage physical activities. Spend time outside when the weather permits. Exercise often helps everyone sleep better.

Incontinence

As the disease progresses, many people with AD begin to experience incontinence, or the inability to control their bladder and/or bowels. Incontinence can be upsetting to the person and difficult for the caregiver. Sometimes incontinence is due to physical illness, so be sure to discuss it with the person's doctor.

- Have a routine for taking the person to the bathroom and stick to it as closely as possible. For example, take the person to the bathroom every 3 hours or so during the day. Don't wait for the person to ask.
- Watch for signs that the person may have to go to the bathroom, such as restlessness or pulling at clothes. Respond quickly.
- Be understanding when accidents occur. Stay calm and reassure the person if he or she is upset. Try to keep track of when accidents happen to help plan ways to avoid them.
- To help prevent nighttime accidents, limit certain types of fluids—such as those with caffeine—in the evening.
- If you are going to be out with the person, plan ahead. Know where restrooms are located, and have the person wear simple, easy-to-remove clothing. Take an extra set of clothing along in case of an accident.

Sleep Problems

For the exhausted caregiver, sleep can't come too soon. For many people with AD, however, nighttime may be a difficult time. Getting the person to go to bed and stay there may require some advance planning.

- Set a quiet, peaceful tone in the evening to encourage sleep. Keep the lights dim, eliminate loud noises, even play soothing music if the person seems to enjoy it.
- Try to keep bedtime at a similar time each evening. Developing a bedtime routine may help.
- Encourage exercise during the day and limit daytime napping.
- Restrict access to caffeine late in the day.
- Use night lights in the bedroom, hall, and bathroom if the darkness is frightening or disorienting.

Hallucinations and Delusions

As the disease progresses, a person with AD may experience hallucinations and/or delusions. Hallucinations are when the person sees, hears, smells, tastes, or feels something that is not there. Delusions are false beliefs from which the person cannot be dissuaded.

- Sometimes hallucinations and delusions are a sign of a physical illness. Keep track of what the person is experiencing and discuss it with the doctor.
- Avoid arguing with the person about what he or she sees or hears. Try to respond to the feelings he or she is expressing, and provide reassurance and comfort.
- Try to distract the person to another topic or activity. Sometimes moving to another room or going outside for a walk may help.
- Turn off the television set when violent or disturbing programs are on. The person with AD may not be able to distinguish television programming from reality.
- Make sure the person is safe and does not have access to anything he or she could use to harm anyone.

Wandering

Keeping the person safe is one of the most important aspects of caregiving. Some people with AD have a tendency to wander away from their home or their caregiver. Knowing what to do to limit wandering can protect a person from becoming lost.

- Make sure that the person carries some kind of identification or wears a medical bracelet. If he or she gets lost and is unable to communicate adequately, this will alert others to his or her identity and medical condition.
- Keep a recent photograph or videotape of the person with AD to assist police if the person becomes lost.
- Keep doors locked. Consider a keyed deadbolt or an additional lock up high or down low on the door. If the person can open a lock because it is familiar, a new latch or lock may help.
- Be sure to secure or put away anything that could cause danger, both inside and outside the house.

Home Safety

Caregivers of people with AD often have to look at their homes through new eyes to identify and correct safety risks. Creating a safe environment can prevent many stressful and dangerous situations.

- Install secure locks on all outside windows and doors, especially if the person is prone to wandering. Remove the locks on bathroom doors to prevent the person from accidentally locking himself or herself in.
- Use childproof latches on kitchen cabinets and anyplace where cleaning supplies or other chemicals are kept.
- Label medications and keep them locked up. Also make sure knives, lighters and matches, and guns are secured and out of reach.
- Keep the house free from clutter. Remove scatter rugs and anything else that might contribute to a fall. Make sure lighting is good both inside and out.
- Consider installing an automatic shut-off switch on the stove to prevent burns or fire.

Driving

Making the decision that a person with AD is no longer safe to drive is difficult, and it needs to be communicated carefully and sensitively. Even though the person may be upset by the loss of independence, safety must be the priority.

- Look for clues that safe driving is no longer possible, including getting lost in familiar places, driving too fast or too slow, disregarding traffic signs, or getting angry or confused.
- Be sensitive to the person's feelings about losing the ability to drive, but be firm in your request that he or she no longer do so. Be consistent—don't allow the person to drive on "good days" but forbid it on "bad days."
- Ask the doctor to help. The person may view the doctor as an "authority" and be willing to stop driving. The doctor also can contact the Department of Motor Vehicles and request that the person be reevaluated.
- If necessary, take the car keys. If just having keys is important to the person, substitute a different set of keys.
- If all else fails, disable the car or move it to a location where the person cannot see it or gain access to it.

Visiting the Doctor

It is important that the person with AD receive regular medical care. Advance planning can help the trip to the doctor's office go more smoothly.

- Try to schedule the appointment for the person's best time of day. Also, ask the office staff what time of day the office is least crowded.
- Let the office staff know in advance that this person is confused. If there is something they might be able to do to make the visit go more smoothly, ask.
- Don't tell the person about the appointment until the day of the visit or even shortly before it is time to go. Be positive and matter-of-fact.
- Bring along something for the person to eat and drink and any activity that he or she may enjoy.
- Have a friend or another family member go with you on the trip, so that one of you can be with the person while the other speaks with the doctor.

Coping with Holidays

Holidays are bittersweet for many AD caregivers. The happy memories of the past contrast with the difficulties of the present, and extra demands on time and energy can seem overwhelming. Finding a balance between rest and activity can help.

- Keep or adapt family traditions that are important to you. Include the person with AD as much as possible.
- Recognize that things will be different, and have realistic expectations about what you can do.
- Encourage friends and family to visit. Limit the number of visitors at one time, and try to schedule visits during the time of day when the person is at his or her best.
- Avoid crowds, changes in routine, and strange surroundings that may cause confusion or agitation.
- Do your best to enjoy yourself. Try to find time for the holiday things you like to do, even if it means asking a friend or family member to spend time with the person while you are out.

Visiting a Person with AD

Visitors are important to people with AD. They may not always remember who the visitors are, but just the human connection has value. Here are some ideas to share with someone who is planning to visit a person with AD.

- Plan the visit at the time of the day when the person is at his or her best. Consider bringing along some kind of activity, such as something familiar to read or photo albums to look at, but be prepared to skip it if necessary.
- Be calm and quiet. Avoid using a loud tone of voice or talking to the person as if he or she were a child. Respect the person's personal space and don't get too close.
- Try to establish eye contact and call the person by name to get his or her attention. Remind the person who you are if he or she doesn't seem to recognize you.
- If the person is confused, don't argue. Respond to the feelings you hear being communicated, and distract the person to a different topic if necessary.
- If the person doesn't recognize you, is unkind, or responds angrily, remember not to take it personally. He or she is reacting out of confusion.

Choosing a Nursing Home

For many caregivers, there comes a point when they are no longer able to take care of their loved one at home. Choosing a residential care facility—a nursing home or an assisted living facility—is a big decision, and it can be hard to know where to start.

- It's helpful to gather information about services and options before the need actually arises. This gives you time to explore fully all the possibilities before making a decision.
- Determine what facilities are in your area. Doctors, friends and relatives, hospital social workers, and religious organizations may be able to help you identify specific facilities.
- Make a list of questions you would like to ask the staff. Think about what is important to you, such as activity programs, transportation, or special units for people with AD.
- Contact the places that interest you and make an appointment to visit. Talk to the administration, nursing staff, and residents.
- Observe the way the facility runs and how residents are treated. You may want to drop by again unannounced to see if your impressions are the same.

- Find out what kinds of programs and services are offered for people with AD and their families. Ask about staff training in dementia care, and check to see what the policy is about family participation in planning patient care.

- Check on room availability, cost and method of payment, and participation in Medicare or Medicaid. You may want to place your name on a waiting list even if you are not ready to make an immediate decision about long-term care.

- Once you have made a decision, be sure you understand the terms of the contract and financial agreement. You may want to have a lawyer review the documents with you before signing.

- Moving is a big change for both the person with AD and the caregiver. A social worker may be able to help you plan for and adjust to the move. It is important to have support during this difficult transition.

For More Information

Several organizations offer information for caregivers about AD. To learn more about support groups, services, research, and additional publications, you may wish to contact the following:

Alzheimer's Association
919 North Michigan Avenue
Suite 1100
Chicago, IL 60611-1676
1-800-272-3900
Web address:
http://www.alz.org

This nonprofit association supports families and caregivers of patients with AD. Almost 300 chapters nationwide provide referrals to local resources and services, and sponsor support groups and educational programs. Online and print versions of publications are also available at the web site.

Alzheimer's Disease Education & Referral (ADEAR) Center
PO Box 8250
Silver Spring, MD 20907-8250
1-800-438-4380
301-495-3334 (fax)
Web address:
http://www.alzheimers.org

This service of the National Institute on Aging is funded by the Federal Government. It offers information and publications on diagnosis, treatment, patient care, caregiver needs, long-term

care, education and training, and research related to AD. Staff answer telephone and written requests and make referrals to local and national resources. Publications and videos can be ordered through the ADEAR Center or via the web site.

Children of Aging Parents
1609 Woodbourne Road, Suite 302A
Levittown, PA 19057-1511
1-800-227-7294
Web address:
http://www.caps4caregivers.org

This nonprofit group provides information and materials for adult children caring for their older parents. Caregivers of people with Alzheimer's disease also may find this information helpful.

Eldercare Locator
1-800-677-1116
Web address:
http://www.aoa.dhhs.gov

The Eldercare Locator is a nationwide, directory assistance service helping older people and their caregivers locate local support and resources for older Americans. It is funded by the Administration on Aging (AoA), which also provides a caregiver resource called *Because We Care - A Guide for People Who Care.* The AoA Alzheimer's Disease Resource Room contains information for families, caregivers, and professionals about AD, caregiving, working with and providing services to persons with AD, and where you can turn for support and assistance.

Family Caregiver Alliance
690 Market Street, Suite 600
San Francisco, CA 94104
415-434-3388
Web address:
http://www.caregiver.org

Family Caregiver Alliance is a community-based nonprofit organization offering support services for those caring for adults with AD, stroke, traumatic brain injuries, and other cognitive disorders. Programs and services include an information clearinghouse for FCA's publications.

The National Institute on Aging Information Center
PO Box 8057
Gaithersburg, Maryland 20898-8057
1-800-222-2225
301-589-3014 (fax)
1-800-222-4225 (TTY)
Web address:
http://www.nia.nih.gov

The National Institute on Aging (NIA) offers a variety of information about health and aging, including the *Age Page* series and the NIA Exercise Kit, which contains an 80-page exercise guide and 48-minute closed-captioned video. Caregivers can find many *Age Pages* on the web site.

Well Spouse Foundation
30 East 40th Street
New York, NY 10016
212-685-8815
1-800-838-0879
Web address:
http://www.wellspouse.org

Well Spouse is a nonprofit membership organization that gives support to wives, husbands, and partners of the chronically ill and/or disabled. Well Spouse publishes the bimonthly newsletter, *Mainstay*.

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